

Kansas Department of Health and Environment
Proposed Amended Permanent Regulation

Screening of Newborn Infants

28-4-501. Definitions. (a) “Applicable income” means the total monies received by all adult members of the family based on any of the following, with the addition of nontaxable benefits from any private, state, and federal funding sources:

(1) The total amount of adjusted gross income reported on one of the federal income tax forms 1040, 1040A, or 1040EZ, including a copy of all W-2 forms filed by each adult member of the family;

(2) the six most recent pay stubs; or

(3) a letter of anticipated earnings from the employer of each adult member of the family if the most recent federal income tax form does not reflect current income.

(b) “Birth attendant” means the person assisting with an out-of-institution delivery of the infant, in the absence of a physician.

~~(b)~~ (c) “Borderline hypothyroid” means an abnormally low level of thyroxine and a higher than normal level of thyroid-stimulating hormone in the blood, the combination of which is not usually indicative of hypothyroidism.

(d) “Cash assets” means accessible money, including savings accounts, certificates of deposit, checking accounts, stocks, and bonds. This term shall not include individual retirement accounts and retirement plans.

~~(e)~~ (e) “Department” means the Kansas department of health and environment.

(f) “Eligible person” means an individual who qualifies for any necessary treatment products or medically necessary food treatment products, or both.

(g) “Family,” for the purposes of these regulations, means an eligible person who meets one of the following conditions and all other persons who reside in the home with the eligible person:

(1) Resides with and is considered to be a dependent of the person’s parents, stepparents, or legal guardian for income tax purposes; or

(2) establishes a separate residence and is no longer considered a dependent of the person’s parents, stepparents, or legal guardian for income tax purposes.

The term “family” shall not include any person who leases or rents a portion of the residence or who lives with the other persons who are not responsible for the financial support of the eligible person.

~~(d)~~ (h) “Galactosemia” means the disease of genetic origin due to galactose uridyl transferase enzyme deficiency in which the individual is completely or partially incapable of normal metabolism of galactose, which results in an abnormal increase in the concentration of galactose in the blood.

~~(e)~~ (i) “Hemoglobin disease” means the presence of abnormal hemoglobin and the absence of adult hemoglobin, the combination of which is indicative of disease and requires ongoing medical treatment.

~~(f)~~ (j) “Hemoglobin trait” means the presence of abnormal hemoglobin, which is not indicative of disease and does not usually require ongoing medical treatment.

~~(g)~~ (k) “Hypothyroidism” means a congenital disease in which the individual is unable to produce thyroxine normally, which may be detected by an abnormally low serum level of thyroxine and abnormally high serum level of thyroid-stimulating

hormone in the blood. For purposes of these newborn screening regulations, this ~~definition~~ term shall exclude diseases referred to as secondary hypothyroidism.

~~(h)~~ (l) “Institution” means a hospital or other organized agency providing obstetrical services.

~~(i)~~ (m) “Kit” means the multiple-page laboratory requisition with the attached filter paper to be used for blood collection and with a place for identifying the infant, physician, and sending agency data. The kits shall be provided by the department.

~~(j)~~ (n) “Laboratory” means the division of health and environmental laboratories, Kansas department of health and environment.

(o) “Maple syrup urine disease” and “MSUD” mean an inherited disease of amino acid metabolism that causes acidosis, central nervous system symptoms, and urine that can smell sweet like maple syrup.

~~(k)~~ (p) “Medical specialist” means a medical doctor who has training in the treatment of a specific disease entity and who ~~is on~~ has a contract with the ~~Kansas~~ department of health and environment to serve as a consultant and to provide or direct diagnosis and treatment services.

(q) “Medically necessary food treatment product” means a specifically formulated product that has less than one gram of protein per serving and is intended to be used under the direction of a physician for the dietary treatment of any inherited metabolic disease. This term shall not include any foods that are naturally low in protein.

(r) “Necessary treatment product” means a medical protein source used under the direction of a physician to treat specific metabolic diseases in order to prevent, delay, or reduce medical complications.

~~(h)~~ (s) “Newborn screening coordinator” means the designee in the department ~~of health and environment~~ providing the follow-up program activities.

~~(m)~~ (t) “Other genetic disease” means any condition inherited in a recognized pattern that ~~may~~ can be detected in a filter paper blood specimen and that the secretary has designated as part of the newborn screening battery of tests.

~~(n)~~ (u) “Phenylketonuria” ~~means~~ and “PKU” mean any disease, usually due to a single enzyme deficiency of genetic origin, in which the individual is completely or partially incapable of normal metabolism of phenylalanine, which results in an abnormal increase in the concentration of phenylalanine in the blood.

~~(o)~~ (v) “Presumptive positive” means a screening test result that indicates the possible presence of ~~the~~ a disease, requiring further testing to confirm or not confirm the diagnosis.

~~(p)~~ (w) “Secretary” means the secretary of the Kansas department of health and environment.

~~(q)~~ (x) “Sending agency” means the agency or person identified on the kit to be the recipient of the report.

~~(r)~~ (y) “Specimen” means the saturated blood spots on the filter paper and the laboratory requisition with complete identifying data on the infant, physician, and sending agency. (Authorized by K.S.A. 65-101 and 65-180, as amended by 2006 SB 579, Sec. 1; implementing K.S.A. ~~1999 Supp. 65-180, as amended by 2006 SB 579, Sec. 1, and 65-181~~; effective, T-87-48, Dec. 19, 1986; effective May 1, 1987; amended April 14, 2000; amended, T-_____, _____; amended P-_____.)